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## **The needs of professionals in the palliative care of children and adolescents**

Bergstraesser, Eva ; Inglin, Susanne ; Abbruzzese, Rosanna ; Marfurt-Russenberger, Katrin ; Hošek, Martin ; Hornung, Rainer

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1 **The needs of professionals in the palliative care of children and adolescents**

2

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20 **Abstract** (206 words)

21 The main objectives of this qualitative study were to describe the perceptions and needs of pediatric health care  
22 professionals (HCPs) taking care of children with palliative care needs, and to develop a concept for the first  
23 Center of Competence for Pediatric Palliative Care (PPC) in Switzerland. Within two parts of the study 76 HCPs  
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27 tasks of specialized PPC teams in Switzerland would encompass the coaching of attending teams, coordination  
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29 *Conclusion* This study indicates the need for specialized PPC in Switzerland both inside and outside of centers  
30 providing top quality medical care (Spitzenmedizin). Specialized PPC teams could have a significant impact on  
31 the care of children and families with PPC needs. Whether hospices are an option in Switzerland remains  
32 unanswered; however, a place to meet other families with similar destinies was emphasized.

33

34 **Keywords:** Palliative Care, Children, Healthcare Professionals, Needs, Specialized Pediatric Palliative Care

35 **Introduction**

36

37 Palliative care, including pediatric palliative care (PPC) with its particular focus on quality of life (QOL) may  
38 lead to better patient and caregiver outcomes [1,26]. Thus, according to the recommendations of the Institute of  
39 Medicine (IOM) [11] and the Association for Children's Palliative Care (ACT) [7], palliative care should be  
40 initiated early in the course of a life-limiting disease. In adults suffering from advanced cancer, randomized  
41 controlled trials have demonstrated that palliative care provided concurrently with standard oncology care not  
42 only improved QOL but also survival [23,25]. Therefore, the American Society of Clinical Oncology (ASCO)  
43 released a provisional clinical opinion that strongly suggests integrating palliative care into standard oncology  
44 care early in the course of illness for patients with metastatic cancer and/or high symptom burden [23]. In  
45 practice, however, palliative care and referrals to specialized PPC services occur comparatively late in the course  
46 of life-limiting diseases in children [8,26]. Individual, structural and cultural barriers to PPC have been  
47 described; some of them may point to uncovered needs of professionals such as specialized PPC support in the  
48 care of these patients [4,14,21,26].

49 In Switzerland there are only few data about the provision of palliative care in the pediatric setting, and to our  
50 knowledge only two tertiary centers offer a specialized PPC service. Besides the University Children's Hospital  
51 of Zurich, the University Children's Hospital of the Canton Vaud has developed a PPC program [6]. To initiate a  
52 service for PPC it appears important to evaluate needs and expectations for such a service from the perspectives  
53 of users, affected families and health care professionals (HCPs), and to also address possible barriers.

54 The main goals of this study were to (1) describe the needs of pediatric HCPs taking care of children with  
55 palliative care needs, and (2) develop a concept for the first Center of Competence for Pediatric Palliative Care  
56 (PPC) in Switzerland.

## 57 **Methods**

58 This study consists of two parts; Part 1 was part of a larger project that included interviews with HCPs as well as  
59 with 15 parents whose child was receiving palliative care or was recently deceased [10]. Part 2 was developed on  
60 the basis of Part 1, to obtain a more detailed view of the needs of HCPs involved in the care of children with life-  
61 limiting diseases. To explore the broad spectrum of heterogeneous perceptions of HCPs including unexpected  
62 aspects and to gain in-depth insight into individual needs and expectations, a qualitative study method with semi-  
63 structured interviews was chosen.

64 In Part 1, we recruited 21 HCPs from four children's hospitals (Aarau, Lucerne, St. Gallen, and Zurich) in  
65 different regions of the German-speaking part of Switzerland. The selection of participants was criterion based  
66 and purposive, covering the most frequent life-limiting diseases (cancer, neurological disorders, and non-  
67 cancer/non-neurological conditions). Neonatology was excluded. From these hospitals, all HCPs contacted  
68 agreed to participate (12 physicians, 5 nurses, and a psychologist, social worker, physiotherapist, pastor and  
69 teacher). To cover aspects of home care as well, two of the nurses were pediatric outpatient nurses (belonging to  
70 the Swiss umbrella organization "Kinderspitex"). All participants had long professional experience but were not  
71 specialized in PPC. Face-to-face interviews were carried out in the participants' work environment from  
72 September 1, 2007 through January 31, 2008. The local ethics committees approved the study procedures.

73 In Part 2, we conducted interviews with 55 HCPs from the University Children's Hospital (n=43) and the Canton  
74 of Zurich (n=43) from February 4, 2009 through August 4, 2009. Of 57 invited professionals 55 agreed to  
75 participate. The sample consisted of experienced and skilled professionals (48/55 with >10 years of professional  
76 experience) and included 18 physicians (without PPC specialization), 19 nurses (some specialized in PPC), as  
77 well as 18 therapists and non-medical carers (social worker, psychologist, pastor, teacher, physiotherapist).

78

### 79 Interview structure and data analysis

80 The interview guide (Table 1) was designed on the basis of international studies and reviews  
81 [3,9,15,17,20,28,29,31] and slightly modified for the additional interviews in Part 2. The questionnaire was pilot  
82 tested with three professionals and revised according to feedback. The second author conducted and transcribed  
83 the interviews for Part 1; the first, third, fourth and fifth authors conducted the interviews for Part 2, and the third  
84 author analyzed these before presenting them to the whole group for further analysis, categorization and ranking.  
85 The process of data analysis, using content analysis [18], has been described in more detail in the first  
86 publication [10].

87 **Results**

88 Results are presented according to overarching themes which emerged from the analysis of the interviews. Table  
89 2 summarizes results with respect to specialties (e.g. oncology, neurology, and other specialties).

90

91 *Definition of “palliative”*

92 The participants in both parts defined “palliative” similarly to the way it is defined by the World Health  
93 Organization (WHO) [37] and the Association for Children’s Palliative Care (ACT) [7], and included aspects  
94 referring to the professionals’ specialization. Thus, oncologists and professionals attached to oncology uniquely  
95 referred to patients with relapses of their primary cancer but also included patients with high-risk tumors or  
96 refractory disease in whom curative and palliative treatment elements may be applied concurrently. Neurologists  
97 described patients with severe progressive conditions who were no longer able to compensate for a deteriorating  
98 impairment, who needed increasing support, or in whom complications occurred more frequently (e.g. recurrent  
99 pneumonia). They also added children with high and complex care needs even if their condition was fairly  
100 stable. Specialists caring for children with cardiac or metabolic diseases, or specialists from a pediatric intensive  
101 care unit (PICU) focused on the goal of treatment and characterized “palliative” patients as those without a  
102 realistic hope of cure or improvement. Nurses pointed out that the child’s autonomy irrespective of age received  
103 more weight in a palliative situation.

104 “I think that palliative care means to live life most consciously until the terminal breath. We should  
105 focus on the needs of the child.” (teacher, hospital school)

106 Some professionals from PICUs had the impression that the term “palliative” was misunderstood as an  
107 abandonment of hope or a sign of capitulation.

108

109 *Attitude toward PPC*

110 It was appreciated that PPC was among the responsibilities of everyone working in pediatrics, and at the same  
111 time, it was emphasized that there was room for improvement. Many staff members felt that there were a  
112 multitude of myths around this part of life as well as barriers to talking about the limits of medicine and about  
113 dying.

114 “Palliative care becomes an issue in my specialty as these patients live longer. The limits of what  
115 cardiology can offer are now moving toward adolescence and young adulthood. - There is a gap of  
116 knowledge and skills concerning how to deal with these young people.” (cardiologist)

117 “For the kids this (PPC) is nearly the most important part of care. We are not allowed to escape.  
118 Unfortunately, there is a tendency to do so.” (specialist in metabolic diseases)

119 “Palliative care is still a taboo in our society and there are many myths around it. We need to talk more  
120 about palliative care issues as these belong to our life and also to our profession.” (general pediatrician)

121

122 Current provision of PPC

123

124 *Composition of teams and mode of practice*

125 All participants reported high flexibility and willingness in the care of these children and families. Flexibility  
126 was also highlighted with respect to place of care, and patients’ needs and wishes. However, two shortcomings  
127 were particularly reported: lack of structures to coordinate the child’s care in hospital or at home, and lack of  
128 human resources to realize individual care during busy shifts or complex situations. Some interviewees were in  
129 favor of the pediatric oncology structures, where, for example, weekly interdisciplinary conferences take place to  
130 exchange information on currently hospitalized patients and patients at home. To insure information flow a  
131 representative of “Kinderspitex” is also present. Some professionals from the hospital, particularly physicians,  
132 were also involved in the care at home by visiting the child and its family, or by meeting the family doctor and  
133 the “Kinderspitex” nurse to discuss treatment or to provide emotional support. Many of these activities happened  
134 outside of working hours.

135 “My dream would be that we were more involved in the care at home. We would visit the patient and  
136 family and support the team at home and thus realize ‘continuity of care’.” (nurse, oncology)

137 “It would be helpful to have some kind of a ‘pool’ which could always allocate an extra nurse to take  
138 over duties; thereby one nurse could stay with the dying child and his or her family.” (nurse, oncology)

139 “For children from neuro-pediatrics, it would be helpful to have round-table discussions like in  
140 oncology or to receive the discharge letter for at least some information about the child.” (nurse,

141 Kinderspitex)

142 In principle, both hospital and “Kinderspitex” nurses noted that the success of care very much depended on the  
143 persons involved, especially physicians. There was substantial agreement among all professionals that support  
144 from a PPC team could improve the current situation, particularly with respect to the coordination of care but  
145 also symptom control.

146 In terms of mode of practice, several professionals outlined areas that needed attention: first, the question of  
147 when to start palliative care; second, decision-making and communication with families; third, standardization of

148 the palliative care setting; fourth, symptom control (particularly pain, dyspnea, fear and agitation); and fifth,  
149 transition to adult palliative care.

150

151 *Communication with parents and the child*

152 Many HCPs reported their unease in talking about dying and death with parents and using the word “dying”. In  
153 contrast, oncologists reported already using “life-threatening” when the diagnosis of cancer is made. However, in  
154 the case of a high probability of death within weeks, physicians did not want to lose time and communicated  
155 more directly. In neurology, the life-limiting character of an illness would also be announced at the time of  
156 diagnosis, and “death” as one scenario might be mentioned as early as that. One cardiologist self-reflected:

157 “Some parents appreciate what the illness is about when clear words are used [...]; following those  
158 conversations, care often becomes much easier.”

159 One physician of a PICU emphasized the setting of this kind of conversation with parents:

160 “It is crucial – and I did not realize this when I was a young doctor, but today I recognize it when  
161 observing colleagues, that they do not choose the best possible setting – parents need a quiet atmosphere  
162 without being interrupted repeatedly. Then they may express their sadness and fears, and may also be  
163 able to cry.”

164

165 *The process of decision-making*

166 A number of participants reported well-planned and interdisciplinary settings (including ethics rounds), when  
167 difficult treatment decisions had to be made, such as changing goals of treatment, withholding or withdrawing  
168 therapy. The conversation with parents would then take place in a more intimate setting, including the doctor and  
169 nurse responsible, and sometimes the psychologist, all having the family’s trust. Parents were allowed to decide  
170 on additional participants (e.g. close friends or a family doctor). The involvement of the child was left up to the  
171 parents. Involving the child was deemed important by nearly all professionals, particularly in older children (>10  
172 years) or if death was expected to occur soon. For the most part, nurses felt integrated in the process of decision-  
173 making. They often played a central role in bridging or channeling the communication with the attending  
174 specialist and in supporting families who frequently addressed their additional questions to a nurse or asked for  
175 her opinion.

176 “Parents want to discuss treatment options and ask what we think about it. We need to be extremely  
177 careful in what we answer. But it is important to demonstrate our willingness to listen and to figure out  
178 what could be helpful to alleviate their process of decision-making.” (nurse, oncology)

179 Irrespective of specialization, many physicians would appreciate guidelines on how to prepare parents who are  
180 going to lose their child. Neurologists expressed needs for advanced care planning and some sort of advanced  
181 directives that could prevent children from unnecessary procedures or treatments in the case of unplanned  
182 admissions. Nurses in particular expressed the need to better document important conversations with the family,  
183 which would also allow parents to review aspects of information. In addition to these documents, brochures on  
184 palliative care or the process of dying could be handed over to the families.

185

#### 186 *Provision of respite care*

187 In Switzerland, families provide a large portion of their child's care when it is suffering from a complex chronic  
188 disease and receive support from "Kinderspitex". Short-term respite care for families burdened with the care of  
189 their child is either provided by "Kinderspitex" or by the hospitals where children may be placed for short  
190 periods. Occasionally "Kinderspitex" staff accompanies families on vacations. In the view of many  
191 professionals, respite care for these families is an unsolved issue in Switzerland. However, the idea of a hospice  
192 was not seen as a fully satisfying solution. Three main reasons were given: 1) parents would not want to be  
193 outside of their home; 2) families would prefer more intensive support in their home; and 3) mothers would feel  
194 even more isolated than at home. On the other hand, particularly physicians and professionals from psychosocial  
195 services reported difficulty in finding financing for such costly care at home, or to find a place for a child with  
196 complex needs to unburden a family or allow some time with healthy siblings. In this context, some physicians  
197 and other professionals valued a hospice as a good place for the provision of respite care. In addition, one  
198 physician envisioned a hospice as a safe place for families to share the fate of a beloved child with a life-limiting  
199 disease. Another physician suggested:

200 "As it already exists for adults, a hospice could provide help with the care at home – stay with a child  
201 overnight to allow parents some rest." (PICU physician)

202 Thus, this issue remained somehow open and inconclusive.

203

#### 204 *Place of death*

205 The place of death appeared to be strongly associated with the diagnosis of the child. Neurologists thought the  
206 hospital was the "better" place of care for children with severe muscular disorders or unexpected acute  
207 deterioration in complex chronic conditions. In addition, the experience of a team regarding palliative and end-  
208 of-life care seemed to influence the place of death. Teams with extensive experience tried hard to enable a family  
209 to care for their dying child at home. Besides giving security and confidence, dying at home was accomplished

210 through continuous phone support, short visits at home or even by accompanying the family when going home.  
211 On the other hand, it was argued that some parents felt lonely with their dying child at their home.

212

### 213 *Bereavement care*

214 Several specialties and wards (particularly PICUs) invite parents to talk about the last days of life and to receive  
215 information about the results of a post-mortem examination. However, no structured bereavement care has been  
216 established so far. Although some professionals wrote condolence cards, attended the funeral or visited the  
217 family, these signs of sympathy depended on one's own initiative and occurred merely occasionally.

218 Within the team, many professionals appreciated the culture of coming together after the death of a child and  
219 sharing experiences about the deceased child or talking about the terminal phase. Thus team members had the  
220 opportunity for debriefing and bringing to a close their personal experience and relationship with the child and  
221 its family.

222

### 223 The needs of professionals

224

### 225 *Particular needs of professionals*

226 Physicians emphasized their need for support and supervision, particularly to improve communication with  
227 parents. They reported that they had never been taught how to do it and seldom received any feedback from  
228 parents or colleagues. Guidelines on how to structure these difficult conversations were thought to be helpful.  
229 Furthermore, it was emphasized that it would be important to develop a network which would facilitate  
230 contacting HCPs with specific knowledge on certain diseases or issues of care and gaining knowledge about the  
231 care of these unique children. Finally, the need for education in palliative care starting in medical school and  
232 continuing through postgraduate training was highlighted. Structure, knowledge and skills should replace the  
233 motto "by instinct" or "learning by doing".

234

### 235 *The role of PPC teams and a Center of Competence of PPC*

236 Three modes of support were predefined: 1) consulting and coaching, 2) teaching, and 3) written guidelines.  
237 In general, the need for a standardized concept of PPC was highlighted. For the provision of PPC, nearly all  
238 physicians and a large proportion of nurses considered the support of a consulting PPC team important. This  
239 would predominantly include team coaching for difficult and complex patients with regard to decision-making,  
240 symptom management and coordination of care. Guidelines and formal teaching were evaluated as being less

241 important, particularly from those working in hospitals. However, to better define patients and families who  
242 might benefit from PPC, an assessment instrument providing objective criteria was deemed desirable. In  
243 addition, there was considerable agreement on the necessity of a standardized concept of bereavement care for  
244 all families affected by the death of a child. For team members, as well, there should be an opportunity to receive  
245 support following the death of a child.

246 **Discussion**

247 This study describes the current situation of PPC in the German-speaking part of Switzerland from the  
248 perspective of HCPs and formulates measures to improve and further develop PPC provision in Switzerland.

249  
250 In contrast to the frequently reported reluctance of HCPs, particularly physicians, to consider a palliative care  
251 approach in an individual patient [4,30] or to involve existing specialized PPC teams [12,21], the generally  
252 positive and open-minded attitude of our study participants toward PPC is remarkable. Besides the recognition  
253 and acceptance of boundaries of what medicine can offer and achieve, PPC emerged as a conceivable and  
254 distinct concept of care that offers a service and network across different settings and thus meets the needs of  
255 families affected by life-limiting illness. A similar encouraging finding has been reported in a survey among 293  
256 German general pediatricians [13], demonstrating a high disposition to engage in palliative care and to involve  
257 specialist PPC consultation teams.

258 Regarding practical implications for PPC in Switzerland, our results encompassed five areas of PPC: 1) when  
259 and how to initiate PPC; 2) the role and tasks of a specialized PPC team; 3) transition from pediatric to adult  
260 services; 4) respite care and the potential role of a hospice; and 5) bereavement care.

261  
262 Despite a rather homogeneous definition of PPC, several difficulties were raised that may interfere with a timely  
263 initiation of PPC. These included an uncertainty about when to start palliative care, uncertain prognoses in many  
264 children, and – probably closely related – unease about communicating a “palliative situation” to parents or to  
265 use the word “dying”. The discomfort related to the term “palliative” and insufficient communication skills are  
266 well known difficulties or even barriers to the provision of PPC [4,5,24,30]. To overcome these, education in  
267 basic palliative care and communication skills in addition to PPC specialist support on site have been highlighted  
268 in previous studies [13,28]. Another reason for discomfort in communication about dying and death could also  
269 be related to moral distress on the part of the HCPs themselves [2,32]; however, to confirm the latter, a more  
270 detailed study approach would be needed.

271  
272 The role and tasks of a specialized PPC teams in Switzerland would primarily include support of hospital- and  
273 home-based teams in the care of a child and its family (e.g. coordination of care and symptom control), and to  
274 some degree the direct support and care of a child. This kind of support has been named ‘consultation service’  
275 and has been described as a reasonable and cost-effective model of care by several groups [19,28,33,34]. With  
276 respect to pediatric subspecialties, the collaboration of specialized PPC teams and pediatric oncology,

277 cardiology, neurology, metabolic diseases and PICUs in tertiary centers and the ongoing involvement of the  
278 specialist, e.g. an oncologist or nephrologist, would ensure disease specific support and continuity of care [22].  
279 Continuity of care may also be achieved by the ongoing involvement of the specialist, e.g. an oncologist or  
280 nephrologist, to ensure disease specific support .

281  
282 Regarding a specialized PPC team in a Center of Competence for PPC, several expectations and wishes were  
283 formulated. These included: developing structures that allow a better coordination of care in hospital or at home;  
284 developing an instrument that would help to identify children with PPC needs; guidelines on aspects of how to  
285 prepare and accompany parents who are going to lose their child; some sort of advanced directives for children  
286 with life-limiting disease to prevent them from unnecessary procedures and treatments; and documents and  
287 information for parents that are accessible for them whenever they need it.

288  
289 In the context of pediatric subspecialties, aspects of transition may need consideration. Hence, children with  
290 congenital heart diseases may successfully undergo surgical interventions and survive childhood; however, they  
291 remain at risk of premature death from progressive heart failure during early adulthood. This has been  
292 demonstrated in a recent publication of Tobler et al. [27] on 48 patients with congenital heart disease who died at  
293 a mean age of  $37\pm 14$  years. They described circumstances of death, end-of-life discussions, and the provision of  
294 end-of-life care, and showed that only a minority of these patients had documented end-of-life discussions prior  
295 to their terminal admission and most of them received continuing aggressive medical treatment up to their  
296 demise.

297  
298 In contrast to our first study, where we reported on parents' preference for home-based respite care [10] rather  
299 than respite care provided by designated hospice houses, a few respondents in the current study elaborated on the  
300 usefulness of a hospice as a place of respite care but also as a safe place for families to share their fate with  
301 others. Particularly physicians and professionals from psychosocial services mentioned the increasing difficulty  
302 of financing costly care at home.

303  
304 The lack of bereavement care for families has been acknowledged in the literature [3,35], and it has been shown  
305 that signs of sympathy have a positive impact on parents' long-term grief outcome [16]. Participants in our study  
306 reported some efforts towards bereavement care several during the terminal stage of a child and after the death of  
307 a child. However, improved structures that facilitate an appropriate and dignified farewell between the families

308 and the professionals are urgently needed. Kreicbergs et al. [16] strongly recommended a closing session with  
309 the attending staff after the death of the child. With respect to long-term support or support in “complicated grief  
310 reactions”, a specialized PPC team, particularly psychologists, could be contacted for further grief counseling by  
311 parents and siblings. Others have reported that interventions or social events to reduce feelings of isolation in  
312 bereaved families are helpful [36].

313

314 There are several limitations to this study. First, the sample is small and heterogeneous and consisted of two  
315 study parts. The reason for this two-part approach was to obtain as many perspectives as possible in a short time.  
316 However, the results may not be generalizable for Switzerland. Second, Part 2 of the study was performed by the  
317 same people who planned to develop the concept for the Center of Competence for PPC and thereby may have  
318 led to a bias in the way that respondents within the same institution formulated critical or negative aspects  
319 concerning the development of PPC.

320

321 Future research, following the first steps of PPC implementation in Switzerland, should embrace a larger sample  
322 of HCPs and also evaluate differences between the German-, French- and Italian-speaking parts of Switzerland.

323

#### 324 **Conclusion**

325 The need for PPC as an overarching specialized service inside and outside of centers providing top quality  
326 medical care (Spitzenmedizin) has been widely acknowledged. PPC should offer a broad range of support for  
327 attending teams as well as for affected families, which particularly includes coaching of teams, coordination of  
328 care, symptom control and bereavement care. Respite care has been recognized as an urgent need for families  
329 who are caring for children with long-lasting complex chronic conditions. Hospices may also be an option in  
330 Switzerland; however there was a debate as to whether families would use them. Apart from that, a place to meet  
331 other families with similar destinies could be a valuable alternative.

332

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336

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424 Table 1 Interview guide  
425

Main topic	Interview question
Definition of palliative care	What does palliative care mean to you? When do you start palliative care in a patient?
Communication and information	How do you communicate a “palliative” situation to the family? How do you announce such a discussion?
Decision-making	What does the process of decision-making look like and who is involved? When and how are parents and patients involved?
Organizational aspects of care	How do you organize the care of an affected child and his or her family in the hospital or at home?
Place of care	Where does the palliative care of children from your specialty take place? How flexibly can you and your team react to changes of place? How is the care coordinated? How can you ensure continuity of care in the hospital and at home?
Provision of respite	How can you provide respite?
Place of death	Where do the children from your specialty die most frequently? With respect to the place of death, what are the most important influencing factors?
Bereavement care*	Do you provide bereavement care? If so, do you use an individual approach or do you have a uniform concept? What does this concept look like?
Needs of professionals	What do you need to feel better prepared in the care of these children and their families (e.g. education, training, support by specialized palliative care teams)? Following the death of a child, how does your team take care of itself?
General judgment of palliative care	What do you think in general about pediatric palliative care? How important is palliative care in your specialty?

426 All questions were supplemented by the question of strengths and shortcomings within the particular issue and  
427 followed by a question about needs for improvement.

428 \* Topics discussed with professionals from the University Children’s Hospital of Zurich and additional  
429 professionals from the Canton of Zurich.

430 Table 2 Composition and mode of practice of existing teams

Specialty	Current situation	Professionals' evaluation		Needs and wishes for the future
		Positive aspects	Negative aspects	
Oncology	Hospital care			
	<ul style="list-style-type: none"> <li>- Regular*: doctors, nurses, psychologists, social worker, nursery school teacher/ teacher, physiotherapist</li> <li>- Optional<sup>o</sup>: pastor</li> </ul>	<ul style="list-style-type: none"> <li>- High commitment and flexibility of all professionals involved in the care of an affected child / family</li> </ul>	<ul style="list-style-type: none"> <li>- Team size often too large</li> </ul>	<ul style="list-style-type: none"> <li>- Team members with PPC training</li> <li>- More flexibility and resources to support home care</li> </ul>
	Home care			
	<ul style="list-style-type: none"> <li>- "Kinderspitex", family doctor (GP, pediatrician), hospital's oncologist</li> </ul>	<ul style="list-style-type: none"> <li>- Well organized "Kinderspitex"</li> </ul>	<ul style="list-style-type: none"> <li>- Lack of training in symptom management</li> <li>- Lack of information about the child's needs ("Kinderspitex")</li> </ul>	<ul style="list-style-type: none"> <li>- PPC team available for support</li> </ul>
Neurology	Hospital care			
	<ul style="list-style-type: none"> <li>- Regular: doctor, nurse</li> </ul>	<ul style="list-style-type: none"> <li>- Patients are mostly at home</li> </ul>	<ul style="list-style-type: none"> <li>- Lack of PPC knowledge (doctors)</li> </ul>	<ul style="list-style-type: none"> <li>- PPC team available for support</li> </ul>
	Home care			
	<ul style="list-style-type: none"> <li>- "Kinderspitex", pediatrician, physiotherapist</li> </ul>	<ul style="list-style-type: none"> <li>- Collaboration with "Kinderspitex"</li> </ul>	<ul style="list-style-type: none"> <li>- Lack of neuro-pediatric and PPC- knowledge</li> </ul>	<ul style="list-style-type: none"> <li>- Improvement of collaboration between specialists and family doctors</li> </ul>
Other specialties (metabolic diseases, cardiology)	Hospital care			
	<ul style="list-style-type: none"> <li>- Regular: doctor, nurse</li> <li>- Optional: pastor, nursery school teacher/ teacher, physiotherapist</li> </ul>	<ul style="list-style-type: none"> <li>- In general good contact with families</li> <li>- Nurses play an important part</li> </ul>	<ul style="list-style-type: none"> <li>- Lack of structure to coordinate care</li> <li>- Lack of continuity and availability of professionals</li> </ul>	<ul style="list-style-type: none"> <li>- Psychologist and social worker as regular team member</li> <li>- Regular meetings with other 'players' (e.g. ER, PICU) to improve exchange of information</li> </ul>

				– For families affected by very rare diseases: a place to meet other families
	– Home care			
	– “Kinderspitex”, pediatrician	– Good collaboration with “Kinderspitex”	– Lack of structures that ensure coordination and continuity of care	– Continuity between hospital and home care – Collaboration with long term institutions

431

432 \*regular means the most common composition of the team; °optional includes additional HCPs in the attending

433 team

434 “Kinderspitex” outpatient nurses; GP general practitioner; ER emergency room